

BARRIERS TO CARE AND PROVIDER INVOLVEMENT IN WEIGHT  
MANAGEMENT FOR YOUTH WITH TYPE 1 DIABETES

by

Madison Watts

Honors Essay

Department of Nutrition

University of North Carolina

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Approved:

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Advisor

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Reader

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## ABSTRACT

Overweight and obesity are common in youth with Type 1 Diabetes (T1D), but no current clinical guidelines focus on weight management in this population. The present study aimed to characterize the patient-perceived experience of and barriers to weight management and to understand the role of the provider in supporting weight management in T1D youth. Participants were youth ages 12-17 with T1D for greater than 1 year and HbA1c < 13% recruited from the University of North Carolina (n=16, 56% female, 60% white, 50% pump users, mean age 14.8, mean HbA1c 8.5%) and the University of Colorado (n=18, 50% female, 80 % white, 53 % pump users, mean age 15.3, mean HbA1c 9.3%). Data were collected through an online questionnaire contained in a secure interface and through focus groups held at the two study sites. The questionnaire used items from the Consumer Assessment of Healthcare Providers and Systems Survey (CAHPS 3.0) to examine the barriers of contextual care, communication and getting information with regards to weight management care. Perceptions of weight management in the context of T1D and the role of provider in weight management care were gathered from focus groups. Focus groups were stratified by gender and weight status (BMI cutoff=25) and guided by a consistent set of questions. Discussions were audio-taped, transcribed, and analyzed using standard inductive qualitative methods. Barriers to weight management care were common in this population. The highest prevalence of barriers was associated with female gender ( $p=0.02$ ) and HbA1c >9% ( $p=0.02$ ), but not weight status. Focus group data indicated that youth feel weight management and T1D care are inherently antagonistic. As a result, youth with T1D report a need to access members of the care team for weight goals and a desire for personalized and T1D-

specific weight-related recommendations to overcome the inherent antagonism between T1D and weight management.

## INTRODUCTION

Type 1 Diabetes Mellitus (T1D) is an autoimmune disorder that results in the destruction of insulin-producing pancreatic beta cells.<sup>1</sup> In the United States more than 1 in 650 youth have T1D,<sup>2</sup> and its incidence continues to increase by 1.8% annually.<sup>3</sup> T1D can cause severe acute complications including hyperglycemia, hypoglycemia, and diabetic ketoacidosis.<sup>4</sup> Patients with chronically uncontrolled diabetes incur macrovascular, microvascular and neurological complications that increase their risk for serious conditions such as neuropathy, retinopathy, nephropathy, and cardiovascular disease.<sup>5</sup> To avoid these complications, which cause the majority of morbidity and mortality, patients are tasked with a self-care regimen that involves frequent blood glucose monitoring, insulin administration, meal planning and medical check-ups to screen for complications.<sup>4</sup>

In 1993, a landmark study called the Diabetes Control and Complications Trial established that strict glycemic management through intensive insulin therapy (IIT) greatly reduced the development and progression of the aforementioned complications.<sup>5</sup> In the decade following this study, the use of IIT in a series of cohorts increased from 52% in 1999 to 97% in 2009.<sup>6</sup> Today, nearly three-fourths of adolescents with T1D use IIT to manage their diabetes.<sup>5,7</sup> The almost universal use of IIT for youth with T1D today is likely attributable to the findings of the DCCT in addition to innovations in the realm of insulin administration and glucose monitoring technology, such as CGM and insulin

pumps. These technologies increased the ease with which one could monitor and treat their diabetes using IIT.

### **Effect of T1D and Weight Status on Cardiovascular Disease Risk**

Despite the many benefits of IIT, the DCCT found inappropriate weight gain as a primary side effect. Patients using IIT faced a 33% increase in risk of being overweight as compared to those using conventional therapy.<sup>5</sup> Furthermore, the follow up-study to the DCCT, called the Epidemiology of Diabetes Interventions and Complications (EDIC) study, found that increased body mass index (BMI) in youth with T1D was associated with an increased risk for cardiovascular disease and atherosclerosis.<sup>8,9</sup> This increase in CVD risk builds upon the baseline risk for youth with T1D, which is already elevated as much as 10-fold compared to youth without diabetes.<sup>10-12</sup> However, weight reduction by as little as 7-10% of body weight has been shown to improve CVD risk factors such as triglyceride levels, HDL-cholesterol levels, blood pressure, hypertensive profiles, and insulin resistance.<sup>13,14</sup>

### **Prevalence of Overweight and Obesity in Youth with T1D**

Simultaneous with the mainstream adoption of IIT and the boom of technology that made insulin administration much easier, was the childhood obesity epidemic in Westernized countries. Over the last 20-30 years, the prevalence of overweight and obesity in U.S. youth has greatly increased, and shows no signs of decreasing.<sup>15,16</sup> Youth with T1D who were already at risk for weight gain based on insulin therapy were also subject to the same factors that caused weight gain in their peers without diabetes. As a result, the prevalence of overweight and obesity has risen in US youth with T1D as much

or more as within US youth in general, according to two large cohort studies.<sup>17,18</sup> The SEARCH for Diabetes in Youth Study containing nearly 4,000 US youth with diabetes and 8,000 US youth without diabetes found that the prevalence of overweight is significantly higher in T1D youth than in the general population (22.1% vs. 16.1%) ( $P < .05$ ) and the prevalence of obesity has begun to mirror that of the general population (12.6% vs. 16.9%).<sup>17</sup> Females and minorities with T1D tended to have a higher prevalence of overweight and obesity. In the age group 12-19, Non-Hispanic White males had the lowest combined prevalence of overweight and obesity (28.8%), while African-American females had the highest prevalence (55.0%), followed by Hispanic males and females (47.8% and 48.7% respectively).<sup>17</sup> The Type 1 Diabetes Exchange (T1DX) registry containing 11,435 U.S. youth echoed these findings. In this population, the prevalence of overweight was 22-24% and the prevalence of obesity was 14-15%, with the range demarking the difference between CDC and WHO standards for defining overweight and obesity.<sup>18</sup> Additionally, median BMI values for this population of T1D youth were found to be higher than national (CDC) and international (WHO) reference values for youth aged 2-18. The T1DX study also looked at markers of cardiovascular disease risk and found that T1D youth who were overweight or obese had 3.5 times the odds of having either hypertension or dyslipidemia.<sup>19</sup>

### **Challenges for Weight Management in the Context of T1D**

Despite the high prevalence of overweight and obesity in youth with T1D and the cardiovascular disease implications it presents, still no clinical guidelines focus on weight management in this population. Insulin-promoted weight gain is one factor that makes weight management more difficult for individuals with T1D, however there may be other

factors that make weight loss uniquely difficult in this population. T1D self-care is extremely complex; in order to achieve optimal glycemic control, youth with T1D engage in a number of daily self-regulation practices including blood glucose monitoring, carbohydrate counting, insulin dosing and treatment of hyper- and hypoglycemic episodes using insulin or rapid-acting carbohydrate, respectively.<sup>20</sup> Additionally, youth with T1D must have a particular consciousness to changes to diet and exercise in order to maintain optimal glycemic control.<sup>20</sup> Diet and exercise affect one's blood sugar, as foods high in carbohydrate raise blood sugar and exercise lowers blood sugar, sometimes to hypoglycemic levels.<sup>21</sup> In turn, one's blood sugar may then dictate immediate dietary choices. Rapid consumption of simple carbohydrate is needed to correct non-severe hypoglycemia, whereas in most other situations carbohydrate intake of youth with T1D must be carefully regulated in order to avoid hyperglycemia.<sup>20</sup> High or low blood sugar may also inhibit one's ability to exercise, as both states produce fatigue, headaches, blurred vision and other symptoms.<sup>20</sup> Because of the adverse short term and long term health effects of both hyper and hypoglycemia, coupled with the fact that there is a strong association between excessive body weight and poor glycemic control in individuals with T1D,<sup>18</sup> glycemic control must take priority for overweight and obese youth with T1D. Therefore, common weight loss strategies based on food restriction may not be effective or feasible in this population. Instead, weight management self-regulation practices must be knitted into the existing web of T1D self-care practices focused on glycemic control, and weight loss strategies must refrain from interfering with insulin dosing, carbohydrate regulation and treatment of hypoglycemic episodes with rapid-acting carbohydrate. With the development of evidence-based weight management practices and guidelines that take

into account the special circumstances that define T1D, there is a potential for dual outcome optimization of weight and glycemic control.

### **Role of Provider in Weight Management Care for T1D Youth**

While T1D does involve a large amount of self-regulation, collaboration with health care providers is critical to disease management.<sup>20</sup> However, a study of 760 youth from the SEARCH cohort found that barriers to care are common in youth with T1D, as they were reported by 81.7% of families.<sup>22</sup> Getting need information from providers (48.7%) was the most frequently reported barrier, followed by cost (47.5%) and provider communication (43%).<sup>22</sup> For the purposes of the study, communication entailed providers always listening carefully and respectfully to their patients, explaining things in a way they could understand, and spending enough time with them. Getting needed information referred to providers making it easy for patients to ask questions and giving specific, helpful answers. Efficient provider-patient communication has been shown in numerous studies to correlate directly with positive health outcomes in a variety of disease contexts,<sup>23,24</sup> with improved adherence to therapy in pediatric cases,<sup>25</sup> and specifically with improved glycemic control in patients with T1D.<sup>26</sup> One such study found that the quality of provider-patient communication was responsible for 21% of the variance in self-care measures such as adherence to taking medications, following diet recommendations, and blood glucose monitoring.<sup>27</sup> Because both T1D care and weight management care require a high level of adherence to behavioral recommendations, provider communication and getting needed information may be acutely important in weight management care for youth with T1D.



While barriers to care have been shown for T1D care as a whole, little is known about the patient-perceived barriers specific to weight management care in T1D youth. For the goal of developing evidence-based recommendations for weight management in this population, a starting point is ascertaining barriers to care based on potential interactions between T1D self-care and weight management self-care as well as barriers related to provider involvement in weight management. A greater understanding of the challenges these youth face and the needs that result will help to aid providers in delivering care that promotes dual outcome optimization of weight and glycemic control.

## **SPECIFIC AIMS**

**AIM 1: To examine provider communication and information flow with regards to weight loss and weight management in youth with T1D using questionnaire responses**

*1a: Communication and information flow as barriers to weight management in youth with T1D:* I hypothesize less effective provider communication and disrupted information flow as barriers to weight management in youth with T1D that are overweight or obese.

*1b: Barriers, HbA1c and weight status:* I hypothesize that those with provider communication as a barrier will have higher HbA1c and weight status (as measured by BMI) than those without this barrier.

**AIM 2: To receive qualitative patient feedback on provider's involvement in weight management, both actual and desired, in youth with T1D using themes of focus group discussion**

*2a: Desired vs. actual provider involvement in weight management:* I hypothesize a gap between actual involvement and desired involvement by T1D youth.

## **METHODS**

TASTE (Teens' Attitudes Surrounding Type 1 Diabetes and Eating) is a pilot study aimed at gathering youth's perceptions of weight loss and maintenance within the context of Type 1 Diabetes (T1D) care. The study involved three components: a questionnaire, a focus group, and a taste test. Questionnaires were used to collect demographic, lifestyle and clinical variables, and also included items to assess disordered eating in diabetes, ingestive behavior, food security, physical activity and barriers to care as it pertains to weight loss. The focus group included several topics related to eating behavior, weight loss attempts, weight management and diabetes care. The taste test was used to provide data on hedonic eating behavior. Data from both the questionnaire and focus groups were used to assess youth's perceptions of both actual and desired provider involvement in weight management for youth with T1D.

### **Participant Inclusion Criteria and Recruitment**

The study was conducted with youth with T1D meeting the following criteria: age 12-17, diabetes duration >1 year, HbA1c <13%. Study recruitment took place at two locations: the University of North Carolina at Chapel Hill (UNC) and the Barbara Davis Center for Diabetes in Denver, Colorado (BDC). At the UNC site, participants were recruited from the UNC Pediatric Endocrinology clinic and the UNC Pediatric Subspecialty Clinic at Rex Healthcare. At the BDC site, participants were recruited from the Barbara Davis Center for Childhood Diabetes. Members of the study team were provided a list of eligible youth from the clinical sites and a script for telephone recruitment. Those who expressed interest over the phone were emailed a personalized information packet with

study details and logistics. Upon confirmation of intent to participate, participants were given an assigned focus group date.

## **Data Collection**

### *Questionnaire*

Upon recruitment into the study, participants were emailed a link to a secure interface with a multi-item questionnaire. Participants were encouraged to complete the questionnaire online before coming to their assigned focus group, but those who had not completed the questionnaire at that time were given a paper version to fill out at the beginning or end of their focus group visit. All data were input into Redcap software.

Demographic and clinical variables were collected at the beginning of the questionnaire, followed by several specialized items. The categories used for race/ethnicity were Hispanic (regardless of race), non-Hispanic white, non-Hispanic black, American Indian, Asian/Pacific Islander, and multiracial (regardless of individual races within).<sup>28</sup>

Disordered eating behavior was assessed using the 16-item Diabetes Eating Problem Survey (DEPS-R) which has been validated for youth aged 13-19 with T1D.<sup>29</sup> Ingestive behavior was measured using three validated instruments: the 15-item Barratt Impulsivity Scale (BIS-15),<sup>30</sup> the 33-item Dutch Eating Behavior Questionnaire (DEBQ),<sup>31</sup> and an adapted version of the 20-item Food Craving Inventory (FCI).<sup>32</sup> The FCI was adapted to include ratings of palatability (like/dislike) alongside ratings of cravings for 20 foods.

Food security was assessed using the USDA 6-Item Food Security Scale.<sup>33</sup> Physical activity and sedentary behavior were measured using a 14-item survey originally designed for the FL3X study for adolescents with T1D.<sup>34</sup> The “Barriers to Weight

Management Care” survey was derived using contextual care, getting information and communication items from the Consumer Assessment of Healthcare Providers and Systems Survey (CAHPS 3.0)<sup>35</sup> as in the SEARCH population of youth with T1D.<sup>22</sup> Participants were asked to consider the items with regards to weight management specifically. The adult format of the survey was used because it was designed for individuals filling out the survey about themselves and their experiences, which was the case with our adolescent-aged cohort. However, question content was identical to the child version aside from pronouns.

### *Focus Group*

Focus groups were designed to ideally contain 4-8 youth and to take between an hour and an hour and a half. Groups were divided by weight status and gender to alleviate sensitivities regarding the discussion of weight. Focus groups were conducted at both sites, UNC and BDC. The study team had the goal of six focus groups per site, with four groups (two all-female, two all-male) consisting of overweight/obese participants with  $BMI \geq 25$  and two groups (one all-female, one all-male) consisting of normal weight participants with  $BMI < 25$ .

Upon arrival to the site, participants signed an assent form and their accompanying parent signed a consent form. Once all participants arrived, a member of the study team lead youth in a discussion about eating behavior and weight loss in the context of T1D using a uniform script. However, facilitators had the freedom to emit questions or ask follow-up questions when appropriate for the individual discussion. Topics addressed included appetite, cravings, weight loss attempts, interplay between T1D care and attempts to maintain or lose weight, barriers faced in weight management, provider involvement in

weight management, how weight management care could be improved, and interest in participation in future studies. The following two questions were specifically included to assess actual and desired provider involvement in weight management care in youth with T1D. However, discussion about provider involvement stemming from other questions or facilitator follow-up was also considered important for data analysis.

**Figure 1** Focus group questions directly related to provider involvement in weight management.

*What could doctors and dieticians do to make weight loss easier?*  
*When you tried to lose weight in the past did you talk to or get help from a physician or a dietician? How helpful was that?*

Upon completion of the questionnaire, focus group and taste test, participants were compensated with a \$50 visa gift card.

## **Data Analysis**

### *Questionnaire*

Questions from the “Barriers to Weight Management Care” survey were divided by barrier category, and each question was scored as barrier or no barrier based on the response indicated (Figure 2). For the contextual care questions, a barrier was indicated by a “no” response and no barrier was indicated by a “yes” response. For communication and getting information a barrier was indicated by anything other than “always” which included the options “often,” “sometimes,” “seldom,” and “never.” This relatively high-cut off scoring method was adopted in the SEARCH study due to research supporting ceiling effects in provider satisfaction surveys conducted with patients.<sup>36</sup>

Barriers to Care	Items	“No Barrier” Response
<b>With regards to weight management...</b>		
<b>Contextual Care</b>	<i>Does this provider talk with you about how you are feeling, growing or behaving?</i>	Yes
	<i>Does this provider understand how your medical, behavioral or other health conditions affect your day-to-day life?</i>	Yes
	<i>Does this provider understand how your medical, behavioral or other health conditions affect your family's day-to-day life?</i>	Yes
<b>Communication</b>	<i>How often does this provider listen carefully to you?</i>	Always
	<i>How often does this provider explain things in a way you can understand?</i>	Always
	<i>How often does this provider show respect for what you had to say?</i>	Always
	<i>How often does this provider spend enough time with you?</i>	Always
<b>Getting Information</b>	<i>How often does this provider make it easy for you to discuss your questions or concerns?</i>	Always
	<i>How often did you have your questions answered by this provider?</i>	Always
	<i>How often did you get the specific information you needed from this provider?</i>	Always

**Figure 2** Barriers to care items selected from the Consumer Assessment of Healthcare Providers and Systems (CAHPS 3.0) and barrier response as modeled in SEARCH population of youth with T1D.<sup>8</sup> Participants were asked to consider their primary provider and the weight management care they’ve received over the last 12 months.

The frequency of barriers (both number and percentage) was calculated for the entire sample and by various demographic and clinical characteristics. Chi square analyses were done to provide p-values for each of the demographic and clinical factors. A t-test was

done to show mean difference in HbA1c and BMI across low barrier (0-1 barriers) and high barrier (2+ barriers) groups. All data analysis was completed in SAS and EpiInfo.

### *Focus Group*

Focus group discussions were digitally recorded with participants' consent and parental assent and transcribed by a member of the study team. Because the study is early formative work, themes were not pre-coded but rather inductively gathered from the focus group transcripts using standard inductive analysis approach.

## **RESULTS**

### **Recruitment and Demographics**

A total of 34 youth with T1D were included in the study. Although the study was designed to have six focus groups per site, only four were held at each because of less than targeted recruitment and indications from the first few focus groups that themes did not vary by weight status. Recruitment outcomes are shown in Table 1. The most common reasons for declining at both sites were that participants were unavailable at the time of their assigned focus group, had transportation issues or were generally disinterested in the study.

	<b>UNC Site</b>	<b>BDC Site</b>
N Eligible	164	231
N Contacted (% of Eligible)	93 (56.7%)	79 (34.2%)
N Expressed Intent to Participate (% of Contacted)	22 (23.7%)	21 (26.6%)
N Participated (% of Contacted)	16 (72.7%)	18 (85.7%)

**Table 1** TASTE recruitment outcomes at both sites



All 34 youth participated in a focus group and completed the questionnaire. Participants had an average age of 14.4 ( $\pm 1.7$ ), an average BMI of 26.1 ( $\pm 4.7$ ), an average HbA1c of 8.9 ( $\pm 1.8$ ) and were majority white, non-Hispanic, pump users (Table 2).

	<b>All</b>	<b>UNC</b>	<b>BDC</b>
N	<i>N=34</i>	<i>n=16</i>	<i>n=18</i>
<b>Demographic Characteristics</b>			
Gender	16M, 18F	7M, 9F	9M, 9F
Age (SD)	14.4 (1.7)	13.7 (1.7)	14.9 (1.6)
BMI (SD)	26.1 (4.7)	24.7 (4.3)	27.5 (3.7)
N White, Non-Hispanic (%)	20 (58.8%)	11 (68.8%)	9 (50.0%)
N Non-White, Non-Hispanic (%)*	8 (23.5%)	5 (31.2%)	3 (16.7%)
N Hispanic (%)	6 (17.6%)	0 (0.0%)	6 (33.3%)
<b>Clinical Characteristics</b>			
HbA1c (%) (SD)	8.9 (1.8)	8.5 (2.0)	9.3 (1.5)
N Pump Users (%)	19 (55.9%)	8 (50.0%)	11 (61.1%)

**Table 2** Demographic and clinical characteristics of TASTE participants. \*Includes African-American, American Indian and Multiracial

The UNC site hosted two all-female groups (one overweight, one normal weight) and two all-male groups (one overweight, one normal weight). The BDC site hosted two all-female overweight groups and two all-male overweight groups. Each of the eight focus groups contained 3-6 individuals (average = 4.25), and lasted between 50 mins and 75 mins (average = 62.5 mins). Individual group composition by site is shown in Table 3.

	UNC	BDC
Overweight Girls 1	FG1: 4 participants Average age: 14.3 (0.5) Average BMI: 29.8 (5.5) Average HbA1c: 7.5 (0.6)	FG2: 4 participants Average age: 14.5 (1.9) Average BMI: 26.5 (1.8) Average HbA1c: 9.9 (1.8)
Overweight Girls 2		FG3: 5 participants Average age: 15.4 (1.5) Average BMI: 29.6 (4.1) Average HbA1c: 9.5 (1.4)
Normal Weight Girls	FG4: 5 participants Average age: 14 (2.3) Average BMI: 21.4 (3.3) Average HbA1c: 8.9 (2.2)	
Overweight Boys 1	FG5: 4 participants Average age: 13.5 (1.9) Average BMI: 26.2 (0.8) Average HbA1c: 9.2 (2.1)	FG6: 6 participants Average age: 14.5 (1.8) Average BMI: 25.4 (3.4) Average HbA1c: 8.8 (1.9)
Overweight Boys 2		FG7: 3 participants Average age: 15.7 (0.6) Average BMI: 29.8 (4.1) Average HbA1c: 9.3 (0.7)
Normal Weight Boys	FG8: 3 participants Average age: 12.7 (1.5) Average BMI: 19.6 (2.6) Average HbA1c: 7.0 (1.5)	

**Table 3** Focus group composition by site. Mean and standard deviation are given for age, BMI, and HbA1c. HbA1c is shown as percentage.

## Questionnaire Data

### *Prevalence of Weight Loss Attempts*

Out of 34 participants, 55.9% reported that they had attempted weight loss at some point, while 38.2% reported that they were currently trying to lose weight (Table 4).

Statistically significant findings include that more females were currently trying to lose weight than males, and that overweight youth chose to eat low fat foods for weight loss purposes more often than their normal weight peers.

	<b>All (N=34)</b>	<b>Overweight (n=26)</b>	<b>Normal Weight (n=8)</b>	<b>Female (n=18)</b>	<b>Male (n=16)</b>
<b>Weight loss attempts:</b>					
Have you ever tried to lose weight?	19 (55.9%)	16 (65.1%)	3 (37.5%)	10 (55.6%)	9 (56.3%)
Are you currently trying to lose weight?	13 (38.2%)	11 (42.3%)	2 (25.0%)	10 (55.6%) +	3 (18.8%)
<b>Actions included in attempts to lose weight:</b>					
Dieted	10 (29.4%)	8 (30.7%)	2 (25.0%)	5 (27.8%)	5 (31.3%)
Exercised	22 (64.7%)	19 (73.1%)	3 (37.5%)	13 (72.2%)	9 (56.3%)
Eaten less food or calories	13 (38.2%)	11 (42.3%)	2 (25.0%)	8 (44.4%)	5 (31.3%)
Eaten low fat foods	10 (29.4%)	10 (29.4%) *	0 (0.0%)	4 (22.2%)	6 (37.5%)
Eaten low carb foods	9 (26.5%)	7 (26.9%)	2 (25.0%)	4 (22.2%)	5 (31.3%)
Drank less SSBs	18 (52.9%)	13 (50.0%)	5 (62.5%)	11 (61.1%)	7 (43.8%)

**Table 4** Weight loss attempts, past and current, stratified by gender and weight status. BMI cutoff = 25. Significance level  $\alpha = 0.05$  used for statistical determinations.

\*statistically significant for overweight as compared to normal weight

+statistically significant for female as compared to male

### *Barriers to Weight Management Care*

Over 70% of participants reported at least one barrier to care. Communication was the most common barrier type, followed closely by getting information. Barriers to contextual care were not as common in this population. Barrier frequency (number of individuals and percentage of the sample) was stratified by select demographic and clinical variables (Table 5).

	<b>N</b>	<b>Any Barrier</b>	<b>Contextual Care</b>	<b>Communication</b>	<b>Getting Information</b>
<b>Overall</b>	N=34	25 (73.5%)	6 (17.6%)	22 (64.7%)	21 (61.7%)
<b>Location</b>					
BDC	n=18	14 (77.8%)	5 (27.8%)	11 (61.1%)	11 (61.1%)
UNC	n=16	11 (68.8%)	1 (6.3%)	11 (68.8%)	10 (62.5%)
<b>Sex</b>					
Male	n=16	9 (56.3%)	1 (6.3%)	7 (43.8%)	7 (43.8%)
Female	n=18	16 (88.9%)	5 (27.8%)	15 (83.3%)	14 (77.8%)
<b>Race/ethnicity</b>					
Non-Hispanic White	n=20	13 (65.0%)	4 (20.0%)	10 (50.0%)	11 (55.0%)
All Other	n=14	12 (85.7%)	2 (14.3%)	12 (85.7%)	10 (71.4%)
<b>HbA1c</b>					
<9.0%	n=19	11 (57.9%)	3 (15.8%)	9 (47.4%)	8 (42.1%)
>9.0%	n=15	14 (93.3%)	3 (20.0%)	13 (86.7%)	13 (86.7%)
<b>BMI</b>					
<25	n=11	8 (72.7%)	1 (9.1%)	8 (72.7%)	8 (72.7%)
>25	n=23	17 (73.9%)	5 (21.7%)	14 (60.9%)	13 (56.5%)

**Table 5** Frequency of barriers by demographic and clinical characteristics.

Barrier frequency was similar across sites, but was higher in females than males and in Hispanics and Non-Hispanic Non-Whites than in their Non-Hispanic White peers. Barrier frequency was also higher in those with most recent clinic HbA1c values higher than 9.0%. Barrier frequency did not appear to differ significantly by weight status.

To examine the contributions of each of the demographic and clinical variables to barrier prevalence, a chi square analysis was done yielding the following p-values (Table 6).

Female sex and HbA1c >9% showed significant associations at the overall level, and within the barrier categories of communication and getting information. Contextual care was not analyzed due to low barrier frequency. Being a racial or ethnicity minority contributed significantly to barrier frequency only in the case of communication barriers.

	<b>Any Barrier</b>	<b>Communication</b>	<b>Getting Information</b>
<b>UNC Location</b>	0.55	0.64	0.93
<b>Female Sex</b>	0.03*	0.02*	0.04*
<b>Hispanic or Non-White Race/ethnicity</b>	0.18	0.03*	0.33
<b>HbA1c &gt;9%</b>	0.02*	0.02*	0.01*
<b>BMI &gt; 25</b>	0.94	0.50	0.36

**Table 6** P-values for chi square analysis of demographic and clinical variables.

The association between HbA1c, BMI and barriers was further analyzed using t-tests. Participants with two or more barrier responses were categorized to a “high barriers” group and participants with one or no barrier responses were considered a “low barriers” group. Those with high barriers had a significantly higher mean HbA1c, but a lower BMI, for which the p-value was slightly larger than significance when using  $\alpha=0.05$ . To

examine whether or not the strict scoring approach had an effect on this association, the analysis was done once again with a less strict cut-off for a “no barrier” response. The mean difference in HbA1c became larger and the p-value more significant even when “often” was included as a no barrier response. There was no significant mean difference in BMI across the low and high barrier group regardless of the scoring method used (Table 7).

“Always” is only no barrier response		
Barriers Group	Mean BMI (SD)	Mean HbA1c (SD)
Low Barriers n=14	27.685 (5.083)	8.186 (1.203)
High Barriers n=20	24.909 (4.077)	9.465 (1.987)
P-value	0.0870	0.0397
“Always” and “often” are both considered no barrier responses		
Barriers Group	Mean BMI (SD)	Mean HbA1c (SD)
Low Barriers n=27	26.080 (5.148)	8.485 (1.450)
High Barriers n=7	25.944 (2.079)	10.686 (2.073)
P-value	0.9466	0.0026

**Table 7** Mean BMI and HbA1c for low and high barriers groups, using both the high-cut off SEARCH scoring classification and the lower-cut off TASTE scoring classification

\*anything besides "always" was considered a barrier response

\*\* count "often" and "always" as no barrier and "never" "seldom" and "sometimes" as barriers

### Focus Group Data

Focus group discussion brought out two major themes for which there was saturation: perceived antagonism between weight management self-care and T1D self-care and a desire for access to multiple members of the provider care team to access diabetes-specific and personalized weight management advice. The idea was that access to

providers who were able to give advice that took into account both processes would help to alleviate some of the antagonism. There were other minor themes for which saturation was not reached, meaning that only one or a few groups reached consensus about them. Some of these are mentioned briefly in order to illustrate the full range of opinions expressed across the groups, but further studies would be needed to confirm the pervasiveness of these perceptions across the total population of youth with T1D or across subgroups within the population.

#### *Provider Involvement in Weight Management*

Six of the eight focus groups explicitly mentioned a desire for involvement of at least one member of the health care provider team in their weight management care. Members of the provider care team that were mentioned included doctors, dietitians and psychologist/psychiatrists. Youth desired their involvement in order to receive help adjusting diabetes care concordantly with changes in diet and exercise (major request) and tips on dieting and exercising to lose weight (minor request). The reason for involving member(s) of the provider care team was most often related to their perceived knowledge on the topic.

This finding was interesting considering the fact that many participants across groups mentioned turning to family members and peers, particularly those with experience or knowledge regarding diet and exercise, more often than doctors and dietitians when beginning a weight loss attempt. Additionally, of those who did mention previous interactions about weight management with doctors or dietitians, not all were positive. Five groups did not specifically mention the quality of previous interactions with doctors and dietitians regarding weight management specifically, but three groups did. In each of

the three groups that discussed previous interactions with providers, there were a few participants with positive commentary. However, from each group there was at least one negative aspect about an interaction that was brought up that was agreed upon by another participant. Youth felt their interactions with providers were hindered by a range of factors that largely deal with a lack of understanding of the patient's circumstances that was inherent in the advice provided or in the way the advice was delivered. The primary factor across several groups was a lack of diabetes-specific weight management care, but other factors that were mentioned by at least one group included a lack of openness to question asking by providers, a lack of understanding of other priorities in youth's lives, a lack of cultural sensitivity and looking at patients "like a number," that number being HbA1c.

*Major Themes: Perceived Antagonism between T1D and Weight Management and the Desire for Personalized and Diabetes-Specific Weight Management Care*

A central theme throughout the entirety of TASTE focus group discussion was the interconnectedness between diet, exercise, blood sugars and insulin. While a few participants felt this interconnectedness created a beneficial interaction between weight management and diabetes care, most groups agreed that efforts to lose weight and efforts to regulate blood sugar were antagonistic. One common example provided by participants is that exercising more in order to lose weight brings blood sugars low, especially if insulin has not been accordingly reduced. Low blood sugar causes one to have to eat more to raise blood sugars again, and in the participant's mind those additional calories defeat the purpose of exercising in the first place. In the face of this challenge, youth expressed a desire for advice from members of the health care team that took into account



the way that changes to diet and exercise affected diabetes care and the way that diabetes care affected attempts to lose weight.

The two most commonly mentioned desires were specific suggestions on how to modify insulin or pump settings in response to changes in diet and exercise and real-time monitoring of blood sugars and food intake via an app with manual entry or via a chip under the skin. These entries would be transmitted to a doctor who could provide periodic suggestions or store the knowledge for future appointments to discuss with youth. There were also requests for advice on foods that wouldn't raise blood glucose as much or exercises that wouldn't lower blood glucose as much for when youth are trying to lose weight. Participants also found favor with planning that took into account the patient's body type and weight loss goals. The idea of a formula was brought that would allow for input of current weight status, weight loss goals, dietary intake, exercise and clinical outcomes (namely blood sugar).

In one of the female overweight groups, there was resentment towards weight management plans designed for the general population, which also illustrates how diabetes-specific planning would be seen as favorable. Things like Weight Watchers and low-carb diets were deemed unreasonable for youth with T1D because they don't leave room for the calories or carbs that are required to manage lows throughout the day.

*Minor Themes: Perception of Distinct Realms of Expertise for Members of the Health Care Provider Team in Weight Management and Desire for Integration*

Despite the fact that the overwhelming narrative of the TASTE focus groups as a whole was the interconnectedness of weight management factors such as diet and exercise and

factors involved in diabetes care like insulin and blood glucose, youth across groups demonstrated the perception that dietitians and doctors have distinct realms of expertise. The idea that, in general, doctors should deal with ‘the diabetes-related stuff’ and dietitians deal with ‘the food-related stuff’ persisted despite a desire for both individuals to have care that took into consideration the factors that may be simultaneously occurring in the other’s department. This finding perhaps evidences the current lack of integration between the topics, and the belief that dietitians aren’t allowed to alter insulin and doctors don’t understand nutrition. The surprising persistence of the distinct realms of expertise idea is remedied by another minor theme of the desire for integration. Youth in a few groups agreed upon the notion that seeing doctors and dietitians together or having them communicate with one another regularly was favorable for their care.

## **DISCUSSION**

The data indicated that barriers to communication and getting information regarding weight management were common in youth with T1D. These youth reported a desire to access multiple members of the provider care team for diabetes-specific and personalized weight management care to overcome the antagonism that they felt was inherent between weight management and T1D.

### *Barriers to Weight Management Care in Youth with Type 1 Diabetes*

A significant amount of literature exists regarding access barriers in youth with special health care needs such as T1D,<sup>37</sup> but less exists regarding process barriers such as contextual care, communication, and getting information. Furthermore, there is a gap in the literature regarding the barriers in the specific context of weight management care for

youth with T1D. The TASTE study population was recruited from endocrinology clinics, so access to care was assumed for these patients. This presented the opportunity to isolate process barriers and determine their influence on youth's perceptions of provider interactions about weight management in the context of T1D.

The TASTE study showed that a substantial proportion of T1D youth experience barriers to high quality care with regards to T1D and weight management. 73.5% of participants experienced at least one barrier to care. Barriers to provider-patient communication and getting needed information were experienced by more than 60% of participants.

Contextual care was less of a problem in this population, as only 17.6% experienced this problem. It is interesting that barriers to contextual care were not common despite verbal discussion in the focus groups regarding a desire for care that took into account one's context, including one's diabetes, culture, adolescent social life and other factors. The frequency of barriers overall was found to be higher in females, Hispanic and Non-Hispanic Non-White youth, and individuals with higher HbA1c levels. Additionally, mean HbA1c was found to be higher in those with more reported barriers, while mean BMI was found to be lower, though the later association never reached significance. These final two findings regarding barriers, demographic factors and clinical variables will be discussed in relation to the SEARCH study<sup>22</sup> and other literature.

#### *Comparison with the SEARCH Population of T1D Youth*

The SEARCH population of U.S. youth with T1D provides the primary source of comparison for results from the TASTE study. The SEARCH study asked barriers to care questions with regards to general T1D care, while the TASTE study asked participants to specifically consider barriers to care with regards to weight management. Comparison of

the two data sources allows one to determine if the barriers experienced with regards to weight management are similar to those experienced with regards to T1D, or if different barriers emerge in the new context.

The frequency of barriers to care in the TASTE population of 34 T1D youth was similar to that of the SEARCH population of 780 T1D youth. In the TASTE study 73.5% of participants experienced at least one barrier, as compared to 81.7% of SEARCH participants.<sup>22</sup> It should be noted that the SEARCH study included three other barriers labeled ‘access barriers’ (regular provider, access to care, and cost of care) in addition to the ‘process barriers’ that were examined in the TASTE study (contextual care, communication and getting information). Getting information and communication, along with cost, were the most prevalent barriers in SEARCH experienced by 48.4% and 43.0% of participants, respectively.<sup>22</sup> In the TASTE cohort, communication was the top barrier experienced by 64.7% of participants followed by getting information at 61.7%.

### *Racial/Ethnic Differences*

In SEARCH there was a significantly higher odds of having any of the three barriers in Hispanic youth than Non-Hispanic Whites.<sup>22</sup> However, there was no significant difference in odds for Non-Hispanic Blacks as compared to their Non-Hispanic White peers.<sup>22</sup> Due to small sample size, TASTE combined Hispanics and Non-Hispanic Blacks and found their combined prevalence of communication barriers to be significantly higher than Non-Hispanic Whites. There is substantial literature that provider-patient communication differs by patient race and ethnicity,<sup>38</sup> and that poorer quality provider-patient interactions are more common in racial and ethnic minorities and often lead to poorer health outcomes.<sup>39</sup> The TASTE study shows that barriers to provider-patient

communication in racial/ethnic youth extend to the realm of weight management and must be considered by clinicians and researchers when developing interventions and protocol to improve health outcomes.

### *Gender Differences*

There was not a difference in barrier frequency by gender observed in SEARCH,<sup>22</sup> though there was a significantly higher prevalence of barriers in females was observed in TASTE. It could be speculated that females may experience more barriers to care with regards to weight management than they do with regards to general T1D care due to sensitivities surrounding weight. It has been shown in the literature that adolescent females are more dissatisfied with their bodies than adolescent males, and are more likely to attempt to lose weight.<sup>40</sup> This was also evidenced by TASTE data showing that more female participants were actively trying to lose weight. Because of this, females may be more likely to interact with providers about weight management or have more invested in the interactions, thus potentially leading to a higher prevalence of perceived barriers. However, studies surrounding female patients discussing weight with providers found that providers are more likely to engage in beneficial motivational-interviewing techniques with females,<sup>41</sup> and that provider-patient agreement with regards to discussion of weight was more likely to happen in females than males.<sup>42</sup> Therefore, more research is needed to examine whether or not there is a higher prevalence of barriers to weight management care in the female population.

### *Association between HbA1c, BMI and Barriers*

In the SEARCH study, t-test analysis showed that mean HbA1c levels were higher in patients who indicated barriers to contextual care, but not barriers to communication or getting information.<sup>21</sup> The SEARCH study did not look at associations between barriers and BMI. With TASTE, mean HbA1c levels were found to be significantly higher in patients with high barriers, but mean BMI was found to be lower in the same group (not statistically significant). Analysis by specific barriers group was not done.

It was surprising to find that the mean HbA1c was significantly higher in the high barriers group despite the fact that the mean BMI was lower considering that weight status has been shown to be significantly associated with poorer glycemic control.<sup>18</sup> The lower BMI in the high barriers group was also counter to the hypothesis that those who were overweight or obese would experience more barriers to weight management care than their normal weight peers. More research involving a larger sample size is needed to examine these conclusions and to conduct multivariate analyses on the interactions between barriers and HbA1c and barriers and BMI, as well as the relationship between HbA1c and barriers.

#### *Perceptions of T1D Youth Regarding Provider Interactions about Weight Management*

Previous interactions with doctors and dietitians regarding weight management were limited in this population of T1D youth, and of those that were mentioned, more were negative than positive. What was lacking in these negative interactions a lack of consideration for the other factors that play a role in the youth's life, particularly their diabetes. Despite these limited and sometimes negative interactions, youth across groups expressed a desire for involvement of doctors and dietitians in weight management in various capacities. They saw doctors and dietitians as having very distinct roles, but

puzzlingly were proponents of bringing weight management and diabetes care together. The dialogue supports the conclusion that perhaps youth feel that currently the roles of the health care provider team are very separate and silohed, but could benefit from further integration which would aid in the deliver of diabetes-specific weight management care, the first and foremost desire of the focus group participants.

### **Strengths and Limitations**

Limitations exist in this study. By nature of being a pilot study, the TASTE study was designed for a smaller number of participants. In addition, small pools of eligible participants and less-than-targeted recruitment outcomes lead to eight focus groups across the two sites rather than twelve. Therefore small sample size is a major limitation of this study, which impacts the ability to conduct advanced statistical analyses and to achieve saturation on minor focus group themes.

#### *Limitations with Barriers to Care Data*

The presence of barriers was indicated by youth self-report using the CAHPS survey. Although the CAHPS survey is a validated instrument, there may be measurement biases present. Also, patients were asked to consider their responses specifically with regard to weight management care, but there is no guarantee that patients who had limited interactions with their providers about weight management care didn't simply consider their diabetes care as a whole. Another limitation is that the survey was scored using a cut-off that classified anything less-than-perfect as a barrier. This choice was made due to evidence of ceiling effects in patient self-report of barriers to care which indicated that an "often" or "sometimes" response can in fact be significantly different from an "always"

response. In regression analysis, associations between barriers and HbA1c not only withheld, but strengthened when barriers were classified with a lower cut-off that included “often” as a no barrier response. However, the study team acknowledges that in reality, barriers may not be dichotomized, but occur more along a spectrum.

### *Limitations to Focus Group Discussion*

In addition, there are limitations inherent in focus group research. A meta analysis of focus group studies conducted with adolescent populations found that common limitations include peer and moderator influence, small group size, wording of questions and interpretive bias of the researcher.<sup>43</sup> In the case of this particular study, using different moderators at the two study sites may have played a role in time spent discussing particular topics. Additionally, sensitivities regarding the discussion of weight may still be present despite stratification of groups by gender and weight status and these could have lead to certain comments or experiences being withheld from group discussion.

### *Strengths*

Strengths of the study include that it is the first of its kind to discuss connections between diabetes care and weight management care, to examine how process barriers and provider interactions shape attempts of T1D youth to maintain or lose weight, and to assess the needs of youth with T1D who are trying to lose weight. Although the sample size was small, the study saw several results that were supported by the SEARCH study and in other literature. Other results had not been heavily evidenced in the literature, but could be unique to the context of weight management care within the T1D population. The



study provides a platform of basic information patient perceptions about weight management care for other researchers and clinicians to use in hypothesis-generation for future research and practice.

## **CONCLUSION**

Both focus group dialogue and barriers to care data indicate that T1D youth are not receiving the highest quality care with regards to weight management. Research in populations other than T1D youth have shown that in the absence of barriers to accessing care,<sup>44</sup> barriers to receiving high quality care can be corrected.<sup>45</sup> There are existing recommendations from the Institute of Medicine<sup>46</sup> that provide evidence-based strategies and interventions for both patients and providers aimed at reducing barriers to provider-patient communication in specific racial/ethnic populations. These recommendations may hold promise for mitigating the observed higher frequencies of barriers in Hispanic and Non-White youth.

The desire of participants for diabetes-specific and personalized weight management care indicates that the current lack of clinical guidelines for weight management specific to T1D youth is a problem. Further research is needed to understand these desires in a larger population that allows for saturation of minor themes and to evaluate the receptiveness of youth towards different provider actions and practices aimed at resolving the inherent antagonism between weight management and T1D. From these further studies, clinical protocol can be developed with the aim of reducing the prevalence of overweight and obesity in T1D youth, optimizing glycemic control and improving cardiovascular health outcomes.

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